437 Fathers' experiences of the emotional impact of managing the care of their children with cystic fibrosis (CF)

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Background: Few studies have consulted fathers of ill children. Limited research on fathers of children with chronic illnesses, however, has identified that they experience more worries and concerns (Hovey, 2003) and express more feelings of lower self esteem (Katz and Krulik, 1999) than fathers of well children.
Aim: To explore fathers' experiences of the emotional impact of managing the care of their children with CF.
Method: Eight Irish fathers of preschool children with CF took part in audio-taped interviews. Data were analysed using thematic content analysis. Rigour of the study was enhanced through the use of verbatim quotations, reflexivity and a decision trail of the research process.
Results: Fathers described living with CF as a constant worry owing to the incessant and unpredictable nature of the disease. Their accounts indicated that they experienced tensions communicating their concerns to others. Although they reported that they spoke to their wives about CF, they indicated that talking about CF was difficult as it caused them to think about it. Despite efforts not to dwell on CF, however, they described being surrounded by constant reminders. Fathers spoke of living from day to day rather than looking into the future as a way of minimising the emotional impact.
Conclusion: These findings demonstrate the need for interventions for fathers to help them voice their concerns and gain support.

References

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438 The voice of experience: listening to those who live with Cystic Fibrosis

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Aims: This study investigated the daily experience of CF patients and their parents living in a regional setting.
Methods: A qualitative methodology – interpretative phenomenology – was used. Data incorporating personal accounts, drawings and poetry was drawn from unstructured interviews involving patients aged from two to twenty-one years old and their parents.
Results: Analysis uncovered eight distinct themes that framed participants' experience: from original fright, through ongoing dynamics of fight and flight, redefined notions of form, familiarity and philosophy, in the pursuit of a future that is both threatened and continually redefined. Of particular magnitude were parents' struggles in the search for new and accurate bearings of information, support and services.
Children revealed growing awareness of, and adaptation to, life with CF. Young adults spoke of negotiating adolescence attended by extraordinary issues such as adherence, death of friends, and lung transplantation.
Conclusion: Giving voice to the circumstances and concerns confronting these families has rendered significant insight. As a result of enhanced knowledge, care can be strategically designed and delivered.

439 Multi-centre questionnaire survey of the incidence, prevalence and severity of urinary stress incontinence in women with CF in Scotland

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Aims: To establish the prevalence, precipitating factors and impact of urinary stress incontinence (USI) in women with CF in Scotland.
Methods: 153 women with CF, age range 16–53 years, attending adult CF units in Aberdeen, Dundee, Edinburgh, Glasgow and Inverness were invited to complete an anonymous, semi-structured questionnaire. The questionnaire was self administered and contained 15 items. The questions related to prevalence, onset, precipitating factors, severity of symptoms plus the physical, social and emotional impact of USI. Issues related to seeking management of this problem were also explored.
Results: Response rate was 70% (n = 107). Prevalence of USI in last year was 53% (n = 56). Onset 16–20 years 36% (n = 21), 21–25 years 14% (n = 8), 26–30 years 9% (n = 5), 31–35 years 7% (n = 4), 36–40 years 7% (n = 4), and 40 years+ 3% (n = 5). The greatest precipitating factors causing mild symptoms (a few drops of leaked urine) was sneezing 81% (n = 47) and those causing moderate to severe symptoms (change of underwear to emptying whole bladder) was coughing 43% (n = 25). The most common activities that patients avoided due to USI were laughing 27% (n = 16) and coughing 24% (n = 14). 79% (n = 46) of patients reported that USI never or rarely interfered with their life, 12% (n = 7) reported quite frequently to frequently and 5% (n = 3) reported very frequently to all the time. 21% (n = 12) of patients had sought help or treatment for this condition. 78% (n = 45) of patients had not done so and the most common reason for this was due to unawareness of treatment 19% (n = 11) and 22% (n = 13) felt that USI was not as serious a condition as CF.
Conclusion: This study confirms a high prevalence and impact of USI in an adult female CF population.

440* "Breathe Easily": An educational program to improve patients' adherence to daily inhalations

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The multi-faceted treatments necessary for the care of CF patients imposes a great burden and impairs their quality of life. Lack of adherence to complex treatment regimens is a frequent problem. The major challenge for patients is the frequency of inhalation therapy which is time-consuming. Non-compliance with inhalation therapy, especially Pulmozyme® which delays the rate of progression of lung disease and is considered standard treatment for mild to moderate lung disease, can have a clinically significant deleterious effect. We hypothesized that lack of knowledge is one of the reasons for reduced adherence. The objective of this study was to evaluate the effect of educational program to improve patient adherence to Pulmozyme® inhalations. 20 patients with CF who use Pulmozyme® inhalations as part of their routine treatment were evaluated with regard to their knowledge regarding the drug, compliance and technical practices associated with the inhalations. The treatment burden was determined by a questionnaire given before and after intervention. Each patient received at least 2 individual 30 minutes sessions one month apart with instructions that included an oral explanation regarding the drug and appropriate techniques of administration, an information sheet, and a compact disc (CD) with illustrations emphasizing lung tissue changes and the mechanism of actions of the medication. Response to the questionnaire assessing patient knowledge pertaining to Pulmozyme® demonstrated that the educational program was effective. Patients, prior to receiving the educational program answered 3.5 + 1.3 (mean + SD) correctly whereas after the intervention, they responded correctly to 5.8 + 0.41 of the questions ($P < 0.001$). Adherence to treatment improved from 40% to 85% ($p < 0.001$).
These results showed that intensive patient education may increase adherence to specific treatment regimens associated with CF.